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JUDICIARY COMMITTEE Testimony regarding HB 7015 An Act Concerning Aid in Dying for Terminally III Patients March 18, 2015

Senator Coleman, Rep. Tong, and members of the Judiciary Committee:

My name is Cathy Ludlum, and I am one of the leaders of Second Thoughts Connecticut, a group of people with disabilities and allies who are working to prevent the legalization of assisted suicide. I am here to voice my opposition to HB 7015.

You may be wondering why we in the disability community are so dedicated to stopping this legislation.

Believe me, we recognize the complexities involved here. Nobody wants people to be dying in pain, desperate, and feeling that they have no control anymore over what is happening in their lives.

Nobody wants that. Especially people with disabilities who know something about what it is to feel like you have no control.

But the harsh reality is that those of us with disabilities will be the collateral damage in any formalized death-by-choice system that is created. For that reason, we have been fighting this, and fighting it hard all over the country. Some have called us "disability hardliners," which we don't understand since we are simply fighting for our lives.

Do you think I'm overstating it? Not at all.

Many of us with severe and obvious disabilities tend to be thought of by medical practitioners as having reached a final stage, where death might be expected in the near future. This may or may not be the case at that particular time; but many of us have experienced the willingness of healthcare workers to give up on us because they do not see any point in continuing to treat us. If we go to the hospital, we bring friends. We have to.

These problems already exist, and are well documented. The last thing we need is for practitioners to have in the back of their minds, "Maybe it's time for 'Aid in Dying."

Any doctor will tell you that medical science is inexact, at best. Sometimes predictions are slightly off, but sometimes they are off by decades.

Look at the case of John Norton, a member of Second Thoughts Massachusetts. He was diagnosed with ALS when he was 18 years old. The diagnosis was verified by the prestigious

Mayo Clinic. For some reason the progression of his disability stopped, and he is alive at the age of 77, with a wife and children, and retired from a successful career. Yet he testifies that if assisted suicide were available 60 years ago, he would have taken advantage of it. Think of all he would have missed based on what was a reasonable prognosis for his condition.

We can spend time picking apart problems with the proposed legislation and trying to design the perfect set of safeguards. Here is a quick list of ways HB 7015 still fails to protect people with disabilities and elders from abuse, and doctors from conflicts of conscience:

- Although heirs and family members are now prohibited from witnessing the written request for the prescription, what is to stop their friends from acting as witnesses?
- Now the request does not need to be made in the presence of a physician but can simply be mailed in. How can we ever know what is going on in that home? Is the ill person being threatened with abandonment? Being told he or she is too much work?
 If the patient is physically unable to write, who is actually making the mailed request?
- "Competent" is defined as allowing a third party to speak for a patient with a
 communication disability if that person claims to be "familiar with a patient's manner
 of communicating." What is to protect a patient with very difficult communication
 from having an exhausted caregiver misrepresent his or her wishes?
- "Self-adminster" merely means to ingest. Nothing in the proposed legislation prevents another person from administering the prescription.
- Likewise, nothing in HB 7015 says that the prescription must be taken orally. Even if the patient consented initially, the drug could be administered to a sleeping patient through a feeding tube without his or her knowledge or consent at that moment.
- No independent witness is required at the death. Was the prescription taken willingly? If the person struggled (or was asleep), who would know?
- There is no investigational authority, so once the prescription is in the home, there is absolutely no protection for the patient, and no ability to look at suspicious cases.
- Doctors will be obligated to falsify death certificates by listing the underlying illness as the cause of death instead of assisted suicide or an overdose of barbiturates.

Unfortunately, adjusting the legislative language does not help. Proponents say that with adequate safeguards, no one is at risk; and every year the proposed bill changes slightly in response to the issues we bring up. Good for you and them for trying to satisfy us!

But in reality, no package of safeguards has ever or CAN ever be developed that will provide 100% protection from

- misdiagnosis
- incorrect prognosis
- coercion
- devaluation of the lives of people with disabilities

Is it acceptable for some lives to be shortened because people are acting on a wrong prognosis, or because they are pressured into making this final move, so that others can exercise what they see as a personal right? My colleagues and I do not want to interfere with anyone's personal choice. But when this choice becomes legislation that poses a direct threat to us and to others in our network, we must emphatically say NO.

There is one more thing. Proponents' repeated statements that there have been no problems with the Oregon and Washington assisted suicide systems are false.

- Kate Cheney died even though several doctors were concerned that she lacked competence and that she was being pressured by her daughter.
- Patrick Matheny died even though he was not physically able to take the medicine without assistance.
- Michael Freeland received the prescription in spite of a long history of acute depression and suicide attempts.

A new report from the Disability Rights Education and Defense Fund describes these and other abuses and shows that the existing safeguards are ineffective. It also describes how a supposedly "peaceful death" goes awry an estimated 15 - 25% of the time from side effects such as vomiting or waking up after a long period of unconsciousness.

Marilyn Golden from DREDF has submitted this report as her testimony on HB 7015. I strongly encourage you to read it before making your decision. Here is the link: http://www.cga.ct.gov/2015/JUDdata/Tmy/2015HB-07015-R000318-Marilyn%20Golden-TMY.PDF

Even if you support this legislation in concept, there is just no way to avoid having some people die for the wrong reasons.

HB 7015 is bad medicine, bad for people, and bad public policy. Please stop it from moving forward.

Thank you for your consideration.